Health Disparities in Epilepsy

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March, 2011
Treatment Gap

“Percentage of patients in a defined population at any given time, with active epilepsy, not receiving treatment”

- Diagnostic
- Surgical
- Medical

Shorvon & Farmer, Epilepsia 1988
Calculating the Treatment Gap
AEDs

\[
\left( \frac{N \text{ PWE}}{N \text{ PWE}} \right) - \left( \frac{N \text{ PWE Treated}}{N \text{ PWE}} \right) \times 100
\]

\( N \text{ PWE} = \text{Number of People with Epilepsy} \)

Shorvon & Farmer, Epilepsia 1988
N PWE

• Door-to-door Survey ** ~ 90% of studies
• Estimated ~ 10% of studies
  – 0.5% of the population **

• Active ** ~ 50% of studies
  – Within last 5 years ** ~70% of studies
  – Within last 1 or 2 years ~ 30% of studies
• Active or Inactive ~ 50% of studies

**Recommended

Epilepsia, 49(9):1491–1503, 2008
N PWE Treated

• Direct Method
  – Door to door survey ** 90% of studies

• Indirect Method ~10% of studies
  – Crude but useful
  – Amount of each type of AED sold in a region
  – Divided by Defined Daily Dose for each AED

**Recommended

Shorvon & Farmer, Epilepsia 1988; Mbuba, Epilepsia 2008
The epilepsy treatment gap in developing countries: A systematic review of the magnitude, causes, and intervention strategies


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**Table 1. Magnitude of the epilepsy treatment gap by region and location**

<table>
<thead>
<tr>
<th>Continent/location</th>
<th>No. of studies</th>
<th>TG (%)</th>
<th>Lower 95% CI</th>
<th>Upper 95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Latin America</td>
<td>7</td>
<td>55.4</td>
<td>39.0</td>
<td>78.6</td>
</tr>
<tr>
<td>Asia</td>
<td>4</td>
<td>64.3</td>
<td>24.3</td>
<td>100.0</td>
</tr>
<tr>
<td>Africa</td>
<td>3</td>
<td>48.9</td>
<td>14.3</td>
<td>100.0</td>
</tr>
<tr>
<td>Urban</td>
<td>7</td>
<td>46.8</td>
<td>34.1</td>
<td>64.2</td>
</tr>
<tr>
<td>Rural</td>
<td>7</td>
<td>73.3</td>
<td>49.5</td>
<td>100.0</td>
</tr>
</tbody>
</table>

_Epilepsia, 49(9):1491–1503, 2008_
Global disparities in the epilepsy treatment gap: a systematic review

Ana-Claire Meyer, Tarun Dua, Juliana Ma, Shekhar Saxena & Gretchen Birbeck

Bull World Health Organ 2010;88:260–266
Causes of Treatment Gap: AEDs

Median and Range

- Unskilled: 70
- High cost: 62
- Unavailability: 53
- Traditional: 44
- Beliefs: 40
- Distance: 18.5

*Epilepsia, 49(9):1491–1503, 2008*
Disparities in Health Care

Systematic differences in the use or receipt of health care services between groups of people who have comparable needs for these services
Disparities in epilepsy: Report of a systematic review by the North American Commission of the International League Against Epilepsy

*Jorge G. Burneo, †Nathalie Jette, ‡William Theodore, §§Charles Begley, ¶Karen Parko, **David J. Thurman, and †Samuel Wiebe for the Task Force

• Systematic Review = 44 articles

<table>
<thead>
<tr>
<th>Access to care</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge &amp; attitudes</td>
<td>9</td>
</tr>
<tr>
<td>Employment, education, disability</td>
<td>7</td>
</tr>
<tr>
<td>Prevalence, Incidence</td>
<td>8</td>
</tr>
<tr>
<td>Outcomes-Medical, Surgical</td>
<td>12, 3</td>
</tr>
</tbody>
</table>

• Predictors analyzed
  – Age, gender, socioeconomic status, race/ethnicity, education, comorbidities

Epilepsia, 50(10):2285–2295, 2009
<table>
<thead>
<tr>
<th></th>
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<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>N patients (range)</td>
<td>30-1430</td>
<td>24-2700</td>
<td>96-313</td>
<td>1000s</td>
<td>64-430</td>
</tr>
<tr>
<td>Population based</td>
<td>2 (40)</td>
<td>4 (44)</td>
<td>1 (14)</td>
<td>8 (100)</td>
<td>0</td>
</tr>
<tr>
<td>Specific populations</td>
<td>3 (60)</td>
<td>5 (56)</td>
<td>6 (86)</td>
<td>0</td>
<td>5 (100)</td>
</tr>
<tr>
<td>Prospective</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2 (25)</td>
<td>4 (80)</td>
</tr>
<tr>
<td>Cross-sectional , Retrospective</td>
<td>5 (100)</td>
<td>9 (100)</td>
<td>7 (100)</td>
<td>5 (63)</td>
<td>1 (20)</td>
</tr>
<tr>
<td>Medical records</td>
<td>1 (20)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3 (60)</td>
</tr>
<tr>
<td>Internal comparison (epilepsy only)</td>
<td>3 (60)</td>
<td>5 (56)</td>
<td>4 (57)</td>
<td>8 (100)</td>
<td>5 (100)</td>
</tr>
<tr>
<td>External comparison (other)</td>
<td>2 (40)</td>
<td>4 (44)</td>
<td>3 (43)</td>
<td>8 (100)</td>
<td>0</td>
</tr>
</tbody>
</table>

*Epilepsia, 50(10):2285–2295, 2009*
Lower Use or Access to Care

- Epilepsy Surgery
  - African Americans – Trend
- AED adherence
  - Lower SES
  - No Insurance or Medicaid
  - Non-Caucasian, Poor communication with clinician
- Mental health services
  - Lower education, AED polytherapy, comorbidity
Type of Health Care
Independent of SES or urban/rural

• Children
  – More Neurologists, ER, hospitalization

• Women
  – More neurologists
  – Fewer Family physician

• Aboriginals (Canada)
  – More ER (x2), hospitalization (x3)
  – Fewer neurologists (X0.3)
• Longitudinal: quarterly surveys x 1 year, 560 clinic attendees
• Four hospitals: 2 NY, 2 Houston, 3 University affiliated,
• Non-Whites compared to Whites
  – GP visits OR 5.3
  – ER visits OR 3.1
  – Hospitalization OR 5.4
  – Specialist OR 0.3
• Differences were largely due to HOSPITAL
  – Worse in University affiliated
• “Where you seek help is more important than who you are”

Socioeconomic status, health care use, and outcomes: Persistence of disparities over time

*Charles Begley, †Rituparna Basu, *David Lairson, *Thomas Reynolds, ‡Stephanie Dubinsky, ‡Michael Newmark, §Forbes Barnwell, ¶Allen Hauser, and #Dale Hesdorffer

Side Effects

<table>
<thead>
<tr>
<th>Quarter</th>
<th>Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quarter 1</td>
<td></td>
</tr>
<tr>
<td>Quarter 2</td>
<td></td>
</tr>
<tr>
<td>Quarter 3</td>
<td></td>
</tr>
<tr>
<td>Quarter 4</td>
<td></td>
</tr>
</tbody>
</table>

Epilepsia 2011
“Coverage Gap”
Coverage of Maternal-Newborn Services

Countdown 2008 Equity Analysis Group

\[
\left( \frac{\text{ORT} + \text{ARI}}{2} + \frac{\text{SBA} + \text{ANC}}{2} + \frac{\text{MSL} + 2\text{DPT3} + \text{BCG}}{4} \right) \frac{1}{4}
\]

where ORT=oral rehydration therapy; ARI=acute respiratory infection; FP=family planning; SBA=skilled birth attendance; ANC=antenatal care; MSL=measles vaccination; and DPT3=three doses of diphtheria, pertussis, and tetanus vaccine.

Countdown, Lancet 371, 2008
Coverage Gap

Designing Interventions

**Barriers**
- Personal/Family
  - acceptability
  - cultural
  - language/literacy
  - attitudes, beliefs
  - preferences
  - involvement in care
  - health behavior
  - education/income
- Structural
  - availability
  - appointments
  - how organized
  - transportation
- Financial
  - insurance coverage
  - reimbursement levels
  - public support

**Use of Services**
- Visits
  - primary care
  - specialty
  - emergency
- Procedures
  - preventive
  - diagnostic
  - therapeutic

**Mediators**
- Quality of providers
  - cultural competence
  - communication skills
  - medical knowledge
  - technical skills
  - bias/stereotyping
- Appropriateness of care
- Efficacy of treatment
- Patient adherence

**Outcomes**
- Health Status
  - mortality
  - morbidity
  - well-being
  - functioning
- Equity of Services
- Patient Views of Care
  - experiences
  - satisfaction
  - effective partnership

Cooper, J Gen Intern Med 2002
• We need
  – Define what is adequate health coverage
  – Identify gaps and effects on health status
  – Identify determinants
  – Understand role of health disparities in general
  – Propose standard methodology
  – Intervene and measure outcomes